

108TH CONGRESS
1ST SESSION

S. 573

AN ACT

To amend the Public Health Service Act to promote organ donation, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Organ Donation and
5 Recovery Improvement Act”.

1 **SEC. 2. SENSE OF CONGRESS.**

2 (a) PUBLIC AWARENESS OF NEED FOR ORGAN DO-
 3 NATION.—It is the sense of Congress that the Federal
 4 Government should carry out programs to educate the
 5 public with respect to organ donation, including the need
 6 to provide for an adequate rate of such donations.

7 (b) FAMILY DISCUSSIONS OF ORGAN DONATIONS.—
 8 Congress recognizes the importance of families pledging
 9 to each other to share their lives as organ and tissue do-
 10 nors and acknowledges the importance of discussing organ
 11 and tissue donation as a family.

12 (c) LIVING DONATIONS OF ORGANS.—Congress—

13 (1) recognizes the generous contribution made
 14 by each living individual who has donated an organ
 15 to save a life; and

16 (2) acknowledges the advances in medical tech-
 17 nology that have enabled organ transplantation with
 18 organs donated by living individuals to become a via-
 19 ble treatment option for an increasing number of pa-
 20 tients.

21 **SEC. 3. REIMBURSEMENT OF TRAVEL AND SUBSISTENCE**
 22 **EXPENSES INCURRED TOWARD LIVING**
 23 **ORGAN DONATION.**

24 Section 377 of the Public Health Service Act (42
 25 U.S.C. 274f) is amended to read as follows:

1 **“SEC. 377. REIMBURSEMENT OF TRAVEL AND SUBSISTENCE**
 2 **EXPENSES INCURRED TOWARD LIVING**
 3 **ORGAN DONATION.**

4 “(a) IN GENERAL.—The Secretary may award grants
 5 to States, transplant centers, qualified organ procurement
 6 organizations under section 371, or other public or private
 7 entities for the purpose of—

8 “(1) providing for the reimbursement of travel
 9 and subsistence expenses incurred by individuals to-
 10 ward making living donations of their organs (in this
 11 section referred to as ‘donating individuals’); and

12 “(2) providing for the reimbursement of such
 13 incidental nonmedical expenses that are so incurred
 14 as the Secretary determines by regulation to be ap-
 15 propriate.

16 “(b) PREFERENCE.—The Secretary shall, in carrying
 17 out subsection (a), give preference to those individuals
 18 that the Secretary determines are more likely to be other-
 19 wise unable to meet such expenses.

20 “(c) CERTAIN CIRCUMSTANCES.—The Secretary
 21 may, in carrying out subsection (a), consider—

22 “(1) the term ‘donating individuals’ as includ-
 23 ing individuals who in good faith incur qualifying ex-
 24 penses toward the intended donation of an organ but
 25 with respect to whom, for such reasons as the Sec-

1 retary determines to be appropriate, no donation of
 2 the organ occurs; and

3 “(2) the term ‘qualifying expenses’ as including
 4 the expenses of having relatives or other individuals,
 5 not to exceed 2, who accompany or assist the donat-
 6 ing individual for purposes of subsection (a) (subject
 7 to making payment for only those types of expenses
 8 that are paid for a donating individual).

9 “(d) RELATIONSHIP TO PAYMENTS UNDER OTHER
 10 PROGRAMS.—An award may be made under subsection (a)
 11 only if the applicant involved agrees that the award will
 12 not be expended to pay the qualifying expenses of a donat-
 13 ing individual to the extent that payment has been made,
 14 or can reasonably be expected to be made, with respect
 15 to such expenses—

16 “(1) under any State compensation program,
 17 under an insurance policy, or under any Federal or
 18 State health benefits program;

19 “(2) by an entity that provides health services
 20 on a prepaid basis; or

21 “(3) by the recipient of the organ.

22 “(e) DEFINITIONS.—For purposes of this section:

23 “(1) The term ‘donating individuals’ has the
 24 meaning indicated for such term in subsection
 25 (a)(1), subject to subsection (c)(1).

“(2) The term ‘qualifying expenses’ means the expenses authorized for purposes of subsection (a), subject to subsection (c)(2).

4 “(f) AUTHORIZATION OF APPROPRIATIONS.—For the
5 purpose of carrying out this section, there is authorized
6 to be appropriated \$5,000,000 for each of the fiscal years
7 2004 through 2008.”.

8 SEC. 4. PUBLIC AWARENESS; STUDIES AND DEMONSTRATIONS.
9

Part H of title III of the Public Health Service Act
(42 U.S.C. 273 et seq.) is amended by inserting after sec-
tion 377 the following:

13 "SEC. 377A. PUBLIC AWARENESS; STUDIES AND DEM-
14 ONSTRATIONS.

“(a) ORGAN DONATION PUBLIC AWARENESS PROGRAM.—The Secretary shall, directly or through grants or contracts, establish a public education program in cooperation with existing national public awareness campaigns to increase awareness about organ donation and the need to provide for an adequate rate of such donations.

“(b) STUDIES AND DEMONSTRATIONS.—The Secretary may make peer reviewed grants or contracts to public and nonprofit private entities for the purpose of carrying out studies and demonstration projects to increase

1 organ donation and recovery rates, including living dona-
 2 tion.

3 “(c) GRANTS TO STATES.—The Secretary may make
 4 grants to States for the purpose of assisting States in car-
 5 rying out organ donor awareness, public education and
 6 outreach activities, and programs designed to increase the
 7 number of organ donors within the State, including living
 8 donors. To be eligible, each State shall—

9 “(1) submit an application to the Department
 10 in the form prescribed;

11 “(2) establish yearly benchmarks for improve-
 12 ment in organ donation rates in the State; and

13 “(3) report to the Secretary on an annual basis
 14 a description and assessment of the State’s use of
 15 these grant funds, accompanied by an assessment of
 16 initiatives for potential replication in other States.

17 Funds may be used by the State or in partnership with
 18 other public agencies or private sector institutions for edu-
 19 cation and awareness efforts, information dissemination,
 20 activities pertaining to the State donor registry, and other
 21 innovative donation specific initiatives, including living do-
 22 nation.

23 “(d) EDUCATIONAL ACTIVITIES.—The Secretary, in
 24 coordination with the Organ Procurement and Transplan-
 25 tation Network and other appropriate organizations, shall

1 support the development and dissemination of educational
 2 materials to inform health care professionals and other ap-
 3 propriate professionals in issues surrounding organ, tis-
 4 sue, and eye donation including evidence-based proven
 5 methods to approach patients and their families, cultural
 6 sensitivities, and other relevant issues.

7 “(e) AUTHORIZATION OF APPROPRIATIONS.—For the
 8 purpose of carrying out this section, there are authorized
 9 to be appropriated \$15,000,000 for fiscal year 2004, and
 10 such sums as may be necessary for each of the fiscal years
 11 2005 through 2008. Such authorization of appropriations
 12 is in addition to any other authorizations of appropriations
 13 that are available for such purpose.

14 **“SEC. 377B. GRANTS REGARDING HOSPITAL ORGAN DONA-**
 15 **TION COORDINATORS.**

16 “(a) AUTHORITY.—

17 “(1) IN GENERAL.—The Secretary may award
 18 grants to qualified organ procurement organizations
 19 and hospitals under section 371 to establish pro-
 20 grams coordinating organ donation activities of eligi-
 21 ble hospitals and qualified organ procurement orga-
 22 nizations under section 371. Such activities shall be
 23 coordinated to increase the rate of organ donations
 24 for such hospitals.

1 “(2) ELIGIBLE HOSPITAL.—For purposes of
 2 this section, an eligible hospital is a hospital that
 3 performs significant trauma care, or a hospital or
 4 consortium of hospitals that serves a population base
 5 of not fewer than 200,000 individuals.

6 “(b) ADMINISTRATION OF COORDINATION PRO-
 7 GRAM.—A condition for the receipt of a grant under sub-
 8 section (a) is that the applicant involved agree that the
 9 program under such subsection will be carried out
 10 jointly—

11 “(1) by representatives from the eligible hos-
 12 pital and the qualified organ procurement organiza-
 13 tion with respect to which the grant is made; and

14 “(2) by such other entities as the representa-
 15 tives referred to in paragraph (1) may designate.

16 “(c) REQUIREMENTS.—Each entity receiving a grant
 17 under subsection (a) shall—

18 “(1) establish joint organ procurement organi-
 19 zation and hospital designated leadership responsi-
 20 bility and accountability for the project;

21 “(2) develop mutually agreed upon overall
 22 project performance goals and outcome measures,
 23 including interim outcome targets; and

24 “(3) collaboratively design and implement an
 25 appropriate data collection process to provide ongo-

1 ing feedback to hospital and organ procurement or-
2 ganization leadership on project progress and re-
3 sults.

4 “(d) RULE OF CONSTRUCTION.—Nothing in this sec-
5 tion shall be construed to interfere with regulations in
6 force on the date of enactment of the Organ Donation and
7 Recovery Improvement Act.

8 “(e) EVALUATIONS.—Within 3 years after the award
9 of grants under this section, the Secretary shall ensure
10 an evaluation of programs carried out pursuant to sub-
11 section (a) in order to determine the extent to which the
12 programs have increased the rate of organ donation for
13 the eligible hospitals involved.

14 “(f) MATCHING REQUIREMENT.—The Secretary may
15 not award a grant to a qualifying organ donation entity
16 under this section unless such entity agrees that, with re-
17 spect to costs to be incurred by the entity in carrying out
18 activities for which the grant was awarded, the entity shall
19 contribute (directly or through donations from public or
20 private entities) non-Federal contributions in cash or in
21 kind, in an amount equal to not less than 30 percent of
22 the amount of the grant awarded to such entity.

23 “(g) FUNDING.—For the purpose of carrying out this
24 section, there are authorized to be appropriated

1 \$3,000,000 for fiscal year 2004, and such sums as may
 2 be necessary for each of fiscal years 2005 through 2008.”.

3 **SEC. 5. STUDIES RELATING TO ORGAN DONATION AND THE**
 4 **RECOVERY, PRESERVATION, AND TRANSPOR-**
 5 **TATION OF ORGANS.**

6 Part H of title III of the Public Health Service Act
 7 (42 U.S.C. 273 et seq.) is amended by inserting after sec-
 8 tion 377B, as added by section 4, the following:

9 **“SEC. 377C. STUDIES RELATING TO ORGAN DONATION AND**
 10 **THE RECOVERY, PRESERVATION, AND TRANS-**
 11 **PORTATION OF ORGANS.**

12 “(a) DEVELOPMENT OF SUPPORTIVE INFORMA-
 13 TION.—The Secretary, acting through the Director of the
 14 Agency for Healthcare Research and Quality shall develop
 15 scientific evidence in support of efforts to increase organ
 16 donation and improve the recovery, preservation, and
 17 transportation of organs.

18 “(b) ACTIVITIES.—In carrying out subsection (a), the
 19 Secretary shall—

20 “(1) conduct or support evaluation research to
 21 determine whether interventions, technologies, or
 22 other activities improve the effectiveness, efficiency,
 23 or quality of existing organ donation practice;

24 “(2) undertake or support periodic reviews of
 25 the scientific literature to assist efforts of profes-

1 sional societies to ensure that the clinical practice
2 guidelines that they develop reflect the latest sci-
3 entific findings;

4 “(3) ensure that scientific evidence of the re-
5 search and other activities undertaken under this
6 section is readily accessible by the organ procure-
7 ment workforce; and

8 “(4) work in coordination with the appropriate
9 professional societies as well as the Organ Procure-
10 ment and Transplantation Network and other organ
11 procurement and transplantation organizations to
12 develop evidence and promote the adoption of such
13 proven practices.

14 “(c) RESEARCH AND DISSEMINATION.—The Sec-
15 retary, acting through the Director of the Agency for
16 Healthcare Research and Quality, as appropriate, shall
17 provide support for research and dissemination of find-
18 ings, to—

19 “(1) develop a uniform clinical vocabulary for
20 organ recovery;

21 “(2) apply information technology and tele-
22 communications to support the clinical operations of
23 organ procurement organizations;

1 “(3) enhance the skill levels of the organ pro-
 2 curement workforce in undertaking quality improve-
 3 ment activities; and

4 “(4) assess specific organ recovery, preserva-
 5 tion, and transportation technologies.

6 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
 7 purpose of carrying out this section, there are authorized
 8 to be appropriated \$2,000,000 for fiscal year 2004, and
 9 such sums as may be necessary for each of fiscal years
 10 2005 through 2008.”.

11 **SEC. 6. REPORT RELATING TO ORGAN DONATION AND THE**
 12 **RECOVERY, PRESERVATION, AND TRANSPOR-**
 13 **TATION OF ORGANS.**

14 Part H of title III of the Public Health Service Act
 15 (42 U.S.C. 273 et seq.) is amended by inserting after sec-
 16 tion 377C, as added by section 5, the following:

17 **“SEC. 377D. REPORT RELATING TO ORGAN DONATION AND**
 18 **THE RECOVERY, PRESERVATION, AND TRANS-**
 19 **PORTATION OF ORGANS.**

20 “(a) IN GENERAL.—Not later than December 31,
 21 2005, and every 2 years thereafter, the Secretary shall re-
 22 port to the appropriate committees of Congress on the ac-
 23 tivities of the Department carried out pursuant to this
 24 part, including an evaluation describing the extent to

1 which the activities have affected the rate of organ dona-
 2 tion and recovery.

3 “(b) REQUIREMENTS.—To the extent practicable,
 4 each report submitted under subsection (a) shall—

5 “(1) evaluate the effectiveness of activities,
 6 identify effective activities, and disseminate such
 7 findings with respect to organ donation and recov-
 8 ery;

9 “(2) assess organ donation and recovery activi-
 10 ties that are recently completed, ongoing, or
 11 planned; and

12 “(3) evaluate progress on the implementation of
 13 the plan required under subsection (c)(4).

14 “(c) INITIAL REPORT REQUIREMENTS.—The initial
 15 report under subsection (a) shall include the following:

16 “(1) An evaluation of the organ donation prac-
 17 tices of organ procurement organizations, States,
 18 other countries, and other appropriate organizations
 19 including an examination across all populations, in-
 20 cluding those with low organ donation rates, of—

21 “(A) existing barriers to organ donation;
 22 and

23 “(B) the most effective donation and re-
 24 covery practices.

1 “(2) An evaluation of living donation practices
2 and procedures. Such evaluation shall include an as-
3 sessment of issues relating to informed consent and
4 the health risks associated with living donation (in-
5 cluding possible reduction of long-term effects).

6 “(3) An evaluation of—

7 “(A) federally supported or conducted
8 organ donation efforts and policies, as well as
9 federally supported or conducted basic, clinical,
10 and health services research (including research
11 on preservation techniques an organ rejection
12 and compatibility); and

13 “(B) the coordination of such efforts
14 across relevant agencies within the Department
15 and throughout the Federal Government.

16 “(4) An evaluation of the costs and benefits of
17 State donor registries, including the status of exist-
18 ing State donor registries, the effect of State donor
19 registries on organ donation rates, issues relating to
20 consent, and recommendations regarding improving
21 the effectiveness of State donor registries in increas-
22 ing overall organ donation rates.

23 “(5) A plan to improve federally supported or
24 conducted organ donation and recovery activities, in-
25 cluding, when appropriate, the establishment of

1 baselines and benchmarks to measure overall out-
 2 comes of these programs. Such plan shall provide for
 3 the ongoing coordination of federally supported or
 4 conducted organ donation and research activities.”.

5 **SEC. 7. NATIONAL LIVING DONOR MECHANISMS.**

6 Part H of title III of the Public Health Service Act
 7 (42 U.S.C. 273 et seq.), is amended by inserting after sec-
 8 tion 371 the following:

9 **“SEC. 371A. NATIONAL LIVING DONOR MECHANISMS.**

10 “The Secretary is authorized to establish and main-
 11 tain mechanisms to evaluate the long-term effects associ-
 12 ated with living organ donations by individuals who have
 13 served as living donors.”.

14 **SEC. 8. STUDY.**

15 Not later than December 31, 2004, the Secretary of
 16 Health and Human Services, in consultation with appro-
 17 priate entities, including advocacy groups representing
 18 those populations that are likely to be disproportionately
 19 affected by proposals to increase cadaveric donation, shall
 20 submit to the appropriate committees of Congress a report
 21 that evaluates the ethical implications of such proposals.

1 **SEC. 9. QUALIFIED ORGAN PROCUREMENT ORGANIZA-**
2 **TIONS.**

3 Section 371(a) of the Public Health Service Act (42
4 U.S.C. 273(a)) is amended by striking paragraph (3).

Passed the Senate November 25, 2003.

Attest:

Secretary.

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1ST SESSION

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AN ACT

To amend the Public Health Service Act to
promote organ donation, and for other purposes.